Being Tested: Client Views of HIV Testing Services

Catherine A. Worthington, Ph.D.
University of Toronto, 2001
Toronto, Canada

Statement of the Research Problem

HIV testing has been a cornerstone of HIV prevention efforts since 1985 when an accurate and reliable test for the HIV antibody became available (Centers for Disease Control and Prevention, 1994, 2001; World Health Organization, 1990). At present, changes in the technology of testing (e.g., rapid point-of-care testing, home testing) and the enhancement of services for specific populations (such as repeat testers or pregnant women) put even greater emphasis on the need for a clear understanding of what happens when the test is applied and the effectiveness of the pre-test and post-test encounters for HIV prevention and/or treatment. In this study, I sought to enhance our understanding of HIV testing through the investigation of clients' perspectives on, and conceptualizations of, testing services.

Statement of the Research Question

To date, most research on HIV testing has been coloured by the assumptions of public health-based service providers. Therefore, research has focussed on desired outcomes associated with HIV testing, particularly HIV risk behaviour change (see summaries in Choi & Coates (1994), Weinhardt et al. (1999), and Wolitski et al. (1997)). The processes of HIV testing have received little attention. As a result, our understanding of service functioning and the dynamics of HIV test counselling is rudimentary (Beardsell & Coyle, 1996; Higgins et al., 1991).

At the centre of HIV testing processes is the test recipient's experience of these processes. The test recipient perspective has been largely neglected in research in this area until very recently. In the broader health and social service sectors, client views of care have received substantial attention over the past several decades. Client participation or 'voice' has been advocated by those who believe in democratizing programs and service systems (Crossley & Crossley, 2001; Winkler, 1987). In addition, health and human service professionals have increasingly acknowledged that the client's perspective is crucial in the provision of high quality services and programs. This perspective is most noticeable in the trend to client- or patient-focussed care at both the clinical and organizational levels in social and medical services (McLaughlin & Kaluzny, 1999; Rapp & Poertner, 1992).

The most widely adopted approach used to investigate client views is patient (or client) satisfaction theory and research. Although satisfaction research has been performed for several decades and many standardized satisfaction instruments and numerous ad-hoc measures have been developed, there are several weaknesses inherent in current

patient/client satisfaction approaches (Avis, Bond, & Arthur, 1997; Sitzia & Wood, 1997). First, most patient/client satisfaction research uses dimensions of care defined by service providers, and represents service provider concerns or service provider perceptions of client concerns. Clients themselves are infrequently asked to define the dimensions of care that are related to service satisfaction. Second, traditional patient/client satisfaction measures have been found to be not particularly useful in discriminating between those who have positive and negative opinions of service. (Overall satisfaction with services is generally found to be very high, often with 85% or more of survey respondents claiming to be satisfied with services.)

Finally, most patient/client satisfaction research has been practical and problem-oriented, and therefore theoretically the area is underdeveloped. The majority of patient/client satisfaction studies implicitly adopt a simplistic disconfirmation model. Within this model, it is assumed that dissatisfaction increases as the disparity between an expected standard of care and perceived occurrences increases (Sitzia & Wood, 1997). Consumer satisfaction research and a small body of sociological research suggests that this primarily cognitive view of satisfaction needs to be augmented with a more complex view of the cognitive elements of satisfaction (i.e., incorporate assimilation and contrast theories), affect (both positive and negative), the social contexts, and interpersonal and power dynamics between patients/clients and care professionals (Avis et al., 1997; Oliver, 1993; Sitzia & Wood, 1997; Williams, Coyle, & Healy, 1998).

This study sought to explore test recipient perspectives on HIV testing services while being sensitive to issues raised by the patient views literature. Given the dearth of information about HIV test recipient perceptions of the test experience; the gaps in, and lack of clarity around, established patient views and satisfaction theory; and the wide range of factors the literature suggests may be relevant to recipients' opinions of care, in this study very basic questions were asked about HIV test recipients' views of care:

1) What do HIV test recipients identify as elements that make up HIV testing services?
2) In what possible ways are these service elements conceptualized by test recipients (i.e., how do test recipients understand the testing processes)?
3) What are some of the more prominent factors (both perceptual and social) related to the perceptions of elements of HIV testing?

Methodology

Given the exploratory nature of the study, a multi-method approach was used, combining extensive qualitative data analysis with supplemental interviews and an exploratory scaling technique (multidimensional scaling (MDS)) to achieve the research objectives.

In the first phase of the research, transcripts from interviews with a purposive sample of 39 voluntary HIV test recipients in Ontario (selected to achieve variation in terms of HIV serostatus, sexual orientation, HIV risk behaviours, geographic region, gender, and testing format (nominal, non-nominal, and anonymous); for further details see Myers et al. (1998)) were analyzed using a grounded theory approach to 1) identify the elements of testing services valued by test recipients and 2) investigate the personal and social factors influencing perceptions of HIV testing. NUD*IST software was used for data analysis (Qualitative Solutions and Research Pty. Ltd., 1996). A colleague review was employed to ensure dependability and credibility of findings. Emergent themes were compared with the existing literature on patient views and HIV care.

In the second phase of the research, supplemental interviews were conducted with a convenience sample of 15 HIV test recipients recruited from a large, urban sexual health clinic to 1) provide confirmation of the HIV test service elements and related themes uncovered during the grounded theory analysis, and 2) explore test recipients' conceptualizations of HIV testing services using a pile sort technique and multidimensional scaling (MDS) analysis. During individual interviews, test recipients were asked to describe their HIV testing experiences, to review a list of test element statements generated from the transcripts and transcript analysis, to add any items they felt were missing to this list, to sort these statements into similarity piles, and then to give labels to the piles they had created. MDS (the ALSCAL module within SPSS software (SPSS Inc., 1997)) was used to summarize the similarities observations and produce numeric and graphical models for interpretation.

Summary of Results

Research Objective 1: Elements of Service

Results suggested diversity in test recipient experiences with HIV testing and complexity and sophistication in their views of testing services. The grounded theory analysis produced a comprehensive set of 28 service elements, including components related to 1) accessibility and availability, 2) structure of the service (privacy, characteristics of the venue and the session, and characteristics of test providers), 3) technical and medical aspects of the testing process (blood-taking, file maintenance, information on technical aspects of the test, obtaining informed consent, the waiting period for test results, and the manner of test result provision), and 4) both cognitive and socio-emotional aspects of the interpersonal process (including decision-making support regarding testing, personalized risk information, the receipt of appropriate emotional support, and referrals to support services). The most prominent elements that emerged from the analysis were those to do with the socio-emotional aspects of the interpersonal process.

Research Objective 2: Test Recipient Understanding of Service Processes

Stress statistics and *r*-square values for the MDS modelling suggested that three- and four- dimensional MDS models produced the most interpretable and parsimonious results. For a non-experimental sample, stress statistics were within the acceptable range

for these models (under .35), and the r-square value was maximized at approximately 20% (not particularly high, but acceptable for a non-experimental study). Results from the MDS analysis suggested that HIV testing services are conceptualized by test recipients in terms of their personal concerns about the testing process. For the small sample employed in the study, these concerns were with *ease* of the testing process (including components of service related to both proficiency of the service and emotional support), *time taken* in the testing process (including components related to efficiency and intensity), *anxiety control* (including components of service that assist with both emotional and cognitive control of anxiety), and *confidence* in the *blood-taking* process (including technical and interpersonal components).

Research Objective 3: Factors related to Service Perceptions

The three dominant social and perceptual themes that emerged from the grounded theory analysis were 1) risk and perceived responsibility for health, 2) the social experience of HIV and stigma, and 3) the power dynamic in the medical relationship. Risk was understood by test recipients as both a statistical probability and a sense of personal danger, and the tension between these two concepts of risk caused anxiety among some respondents (e.g., feeling threatened even though the probability of having HIV was statistically low). Risk was also felt by most of the test recipients to be a personal responsibility, as were health and health behaviours more generally. The stigma experienced around HIV and HIV testing was also a prominent theme. This was often coupled with feelings of stigmatization around other characteristics (e.g., sexual orientation, injection drug use, ethnocultural group). The power dynamic in the medical relationship also emerged as a prominent theme. Test recipients were very conscious of their power (or lack thereof) in their relationship with their test provider, and four techniques were reported that enhanced test recipient feelings of control within the testing situation. These included withholding or controlling the amount of information provided; letting the test provider know preferences; challenging information, decisions, or exhibited attitudes; and, at the extreme, changing test or health care providers. These three themes are important contextual factors influencing HIV test recipients' views of testing services.

Utility for Social Work Practice

The results of this study suggest that clients understand the components of quality care and that their perspectives can be used to help service providers both develop and improve areas of service. Test recipients were able to describe a comprehensive set of service elements, and their comments, taken together, revealed a sophisticated understanding of the issues surrounding HIV testing. Client perspectives on other types of services (e.g., mental health services, home care, child welfare) would be as illuminating.

Given the emphasis on the socio-emotional aspects of HIV testing services, commentary from test recipients suggests that additional information on, and training in, counselling and listening skills for both physician and non-physician test counsellors could improve testing services from the test recipient perspective. Desired service characteristics will not be unfamiliar to social workers. Test recipients emphasized the need for

individualized care, and expected their individual attributes and circumstances to be recognized during the HIV testing process. Ideally, this means that test recipients should be able to have a choice in their testing service options, and within the test sessions, to receive individualized information and counselling rather than a standardized process and pre-formatted information.

The social and perceptual themes identified in the grounded theory analysis emphasized the need to be sensitive to experiences and perceptions regarding risk and stigma, and also to be sensitive the power dynamic between client and professional. These findings are consistent with the emerging literature on patient views of care, patient-physician interaction models, and, within social work, with the emphasis on the therapeutic alliance as the foundation for effective interventions. Social work practice models such as the strengths perspective and the empowerment approach emphasize clients' roles as competent participants in structuring their professional interactions. Results are consistent with this view of the client.

Finally, the results of the similarities pile sort and MDS analysis suggest that additional understanding of client views of services may be gained by investigating client conceptualizations of service processes. Understanding what service processes are about from the client perspective may open up new ways of evaluating, organizing, and managing service provision.

Acknowledgements: Financial support provided in part by the Social Sciences and Humanities Research Council of Canada (SSHRC), and by the Ontario HIV Treatment Network (OHTN). The author wishes to express her gratitude to study participants, colleagues at the HIV Social, Behavioural and Epidemiological Studies Unit, University of Toronto, thesis committee members Ted Myers, Lilian Wells, Wes Shera, Adrienne Chambon (all at the University of Toronto), and external reviewer Bill Rowe (at McGill University).

References

Avis, M., Bond, M., & Arthur, A. (1997). Questioning patient satisfaction: an empirical investigation in two outpatient clinics. *Social Science and Medicine, 44*(1), 85-92.

Beardsell, S., & Coyle, A. (1996). A review of research on the nature and quality of HIV testing services: A proposal for process-based studies. *Social Science and Medicine, 42*(5), 733-743.

Centers for Disease Control and Prevention. (1994). *HIV counseling, testing and referral standards and guidelines.*: U.S. Department of Health and Human Services, Public Health Service.

Centers for Disease Control and Prevention. (2001). *HIV Prevention Strategic Plan Through 2005.*: Centers for Disease Control and Prevention.

Choi, K.-H., & Coates, T. J. (1994). Prevention of HIV infection. *AIDS, 8*, 1371-1389.

Crossley, M. L., & Crossley, N. (2001). 'Patient' voices, social movements and the habitus; how psychiatric survivors 'speak out'. *Social Science and Medicine, 52*, 1477-1489.

Higgins, D. L., Galavotti, C., O'Reilly, K. R., Schnell, D. J., Moore, M., Rugg, D. L., & Johnson, R. (1991). Evidence for the effects of HIV antibody counseling and testing on risk behaviors. *Journal of the American Medical Association, 266*(17), 2419-2431.

McLaughlin, C. P., & Kaluzny, A. D. (1999). *Continuous Quality Improvement in Health Care: Theory, Implementation, and Applications*. Gaithersburg, MD: Aspen Publishers Inc.

Myers, T., Haubrich, D., Mahoney, D., Calzavara, L., Cockerill, R., Millson, P., Worthington, C., & Ryder, K. (1998). *The HIV test experience study*. Toronto: HIV Social Behavioural and Epidemiological Studies Unit, Faculty of Medicine, University of Toronto.

Oliver, R. L. (1993). Cognitive, affective and attribute bases of the satisfaction response. *Journal of Consumer Research, 20*, 418-430.

Qualitative Solutions and Research Pty. Ltd. (1996). NUD*IST Non-numerical Unstructured Data Indexing, Searching and Theorizing. Sydney, Australia: Qualitative Solutions and Research Pty. Ltd.

Rapp, C. A., & Poertner, J. (1992). *Social administration: A client-centered approach*. New York: Longman.

Sitzia, J., & Wood, N. (1997). Patient satisfaction: A review of issues and concepts. *Social Science and Medicine, 45*(12), 1829-1843.

SPSS Inc. (1997). SPSS for Windows (Version Release 8.0.0). Chicago: SPSS.

Weinhardt, L. S., Carey, M. P., Johnson, B. T., & Bickham, N. L. (1999). Effects of HIV counseling and testing on sexual risk behavior: a meta-analytic review of published research, 1985-1997. *American Journal of Public Health, 89*(9), 1397-1405.

Williams, B., Coyle, J., & Healy, D. (1998). The meaning of patient satisfaction: an explanation of high reported levels. *Social Science and Medicine, 47*(9), 135101359.

Winkler, F. (1987). Consumerism in health care -- beyond the supermarket model. *Policy and Politics, 15*, 1-8.

Wolitski, R. J., MacGowan, R. J., Higgins, D. L., & Jorgensen, C. M. (1997). The effects of HIV counseling and testing on risk-related practices and help-seeking behavior. *AIDS Education and Prevention, 9* (Supplement B), 52-67.

World Health Organization. (1990). *Guidelines for counselling about HIV infection and disease*. Geneva, Switzerland: WHO Series 8, Global Programme on AIDS.